

118TH CONGRESS
2D SESSION

H. R. 10484

To direct the Secretary of Health and Human Services to carry out a public awareness campaign to increase participation by women in clinical trials that are conducted or supported by the National Institutes of Health, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

DECEMBER 18, 2024

Mr. GOTTHEIMER (for himself and Ms. PETTERSEN) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To direct the Secretary of Health and Human Services to carry out a public awareness campaign to increase participation by women in clinical trials that are conducted or supported by the National Institutes of Health, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Securing Equal Access
5 to Research, Care, and Health Act of 2024” or the
6 “SEARCH Act of 2024”.

1 **SEC. 2. PUBLIC AWARENESS CAMPAIGN TO INCREASE PAR-**
2 **TICIPATION OF WOMEN IN NIH CLINICAL**
3 **TRIALS.**

4 (a) IN GENERAL.—The Secretary of Health and
5 Human Services (in this Act referred to as the “Sec-
6 retary”), acting through the Director of the National In-
7 stitutes of Health, shall carry out a public awareness cam-
8 paign to increase the participation of women in clinical
9 trials conducted or supported by the National Institutes
10 of Health.

11 (b) TARGETED OUTREACH.—In carrying out the
12 campaign under subsection (a), the Secretary shall in-
13 crease outreach at hospitals, physicians’ offices, health
14 centers, health care clinics, and other locations that the
15 Secretary determines appropriate.

16 (c) PRIORITY.—In carrying out the campaign under
17 subsection (a), the Secretary shall prioritize increasing the
18 participation of women in clinical trials involving research
19 on, and development of, products to prevent, diagnose, or
20 treat, rare diseases and conditions.

21 (d) AUTHORIZATION OF APPROPRIATIONS.—To carry
22 out this section, there is authorized to be appropriated
23 \$10,000,000 for each of fiscal years 2025 through 2029.

1 **SEC. 3. PUBLIC AWARENESS CAMPAIGN TO INCREASE**
2 **AWARENESS OF BLEEDING AND CLOTTING**
3 **DISORDERS IN WOMEN.**

4 (a) IN GENERAL.—The Secretary of Health and
5 Human Services shall carry out a public awareness cam-
6 paign to increase the number of women participating in
7 programs of the Department of Health and Human Serv-
8 ices for research, surveillance, and prevention with respect
9 to bleeding and clotting disorders, including hemophilia.

10 (b) AUTHORIZATION OF APPROPRIATIONS.—To carry
11 out this section, there is authorized to be appropriated
12 \$10,000,000 for each of fiscal years 2025 through 2029.

13 **SEC. 4. INTERAGENCY TASK FORCE ON ADVANCING TREAT-**
14 **MENTS FOR RARE DISEASES.**

15 Part A of title III of the Public Health Service Act
16 (42 U.S.C. 241 et seq.) is amended by adding at the end
17 the following:

18 **“SEC. 310C. INTERAGENCY TASK FORCE ON ADVANCING**
19 **TREATMENTS FOR RARE DISEASES.**

20 “(a) IN GENERAL.—The Secretary shall maintain a
21 permanent task force, to be known as the Interagency
22 Task Force on Advancing Treatments for Rare Diseases
23 (in this section referred to as the ‘Task Force’). The Sec-
24 retary shall establish the Task Force not later than 90
25 days after the date of enactment of the SEARCH Act of
26 2024.

1 “(b) COMPOSITION.—The Task Force shall be com-
2 posed of the following members:

3 “(1) The Secretary.

4 “(2) The Administrator of the Centers for
5 Medicare & Medicaid Services.

6 “(3) The Commissioner of Food and Drugs.

7 “(4) The Director of the National Institutes of
8 Health.

9 “(5) The Director of the Centers for Disease
10 Control and Prevention.

11 “(6) Four individuals, to be appointed by the
12 Secretary, who are—

13 “(A) biopharmaceutical innovators with re-
14 spect to rare diseases and conditions;

15 “(B) private health plan administrators; or

16 “(C) representatives of institutions or or-
17 ganizations conducting federally funded re-
18 search with respect to rare diseases and condi-
19 tions.

20 “(7) Four individuals, to be appointed by the
21 Secretary, who are representatives of rare disease
22 advocacy groups.

23 “(c) DUTIES.—The Task Force shall—

24 “(1) assess—

1 “(A) Federal agency activities concerning
2 rare diseases, including projects involving two
3 or more agencies;

4 “(B) overall programmatic funding; and

5 “(C) potential measurable outcomes to in-
6 clude in future reports; and

7 “(2) coordinate the efforts of the Department
8 of Health and Human Services to incentivize re-
9 search on, and development of, products for preven-
10 tion, diagnosis, and treatment with respect to rare
11 diseases and conditions, particularly rare diseases
12 and conditions that disproportionately impact
13 women.”.

14 **SEC. 5. ACTION PLAN FOR COORDINATING HHS EFFORTS**
15 **WITH RESPECT TO CERTAIN RARE DISEASES**
16 **AND CONDITIONS.**

17 (a) IN GENERAL.—The Secretary shall prepare an
18 action plan for coordinating efforts of the Department of
19 Health and Human Services to incentivize research on,
20 and development of, products for prevention, diagnosis,
21 and treatment with respect to rare diseases and conditions
22 that disproportionately impact women.

23 (b) SUBMISSION AND PUBLIC AVAILABILITY.—Not
24 later than 180 days after the date of enactment of this
25 Act, the Secretary shall—

1 (1) complete the action plan required by sub-
2 section (a);

3 (2) submit such action plan to the Congress;
4 and

5 (3) make such plan publicly available, including
6 by posting on the websites of the Department of
7 Health and Human Services and the National Insti-
8 tutes of Health.

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